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## ABSTRACT

Although the incidence of fetal alcohol syndrome (FAS) has been called an "epidemic" on some American Indian reservations, solutions for Native American women with alcohol and drug dependency problems have largely been ignored by the federal government. FAS prevention policy, originating around 1979, has been driven by the simplistic idea that women are responsible for FAS, and has focused primarily on the health of the fetuses, not of the women themselves. Long-standing policy has ignored the dearth of gender-sensitive treatment programs for women, the devastating health consequences of alcohol use for all Native Americans, and the complex conditions that give rise to alcohol dependency. Tribes, especially those in rural areas, have limited access to federal funding for FAS prevention, and existing funding methods complicate service delivery. FAS prevention has meant, largely, that the federal government gives money to tribes to distribute educational materials and to identify those suffering from FAS, and gives money to the Centers for Disease Control and other agencies for surveillance studies. Existing FAS prevention efforts are largely unworkable due to gender insensitivity, lack of child care, social stigma, bureaucratic infighting, lack of interagency coordination, and lack of adequately trained staff. Although "primary prevention workers" have recently begun providing training to educators, related health education to children, and support and referral services, such workers are scarce and scattered. (SV)

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# CHARTING A NEW COURSE: FINDING ALCOHOL TREATMENT FOR NATIVE AMERICAN WOMEN

By Kary L. Moss, Esq. (ALL RIGHTS RESERVED)

## Introduction

Betty was 26 years old and pregnant when police arrested her a year and a half ago for abusing her six year old daughter. Betty suffers from Fetal Alcohol Syndrome (FAS), a birth defect caused primarily by maternal drinking during pregnancy. She is an alcoholic and her daughter suffers from Fetal Alcohol Effect (FAE). Instead of putting her in jail, the police sent Betty to the Native American Rehabilitation Program (NARP) in Oregon, one of the few alcohol treatment programs in the country that has tried to help women with FAS and FAE. Were it not for this program, Betty would be in jail. Instead, she's sober.

Many believe that women who suffer from FAS or FAE are untreatable, a conclusion which gained popularity after Michael Dorris published The Broken Cord several years ago. Yet it was only last year that the Indian Health Service (IHS) funded the first treatment program to serve Native American women exclusively -- the American Indian Family Healing Center located in Oakland, California. And it was only recently that other treatment programs began working with this population -- the Guiding Star Lodge, in Arizona, and NARP. Today only six programs provide co-ed treatment. In all, 11 percent of IHS inpatient programs are devoted in some way to women's treatment. IHS expects to allocate \$2 million this year to women's programs.

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The good news is that treatment providers are finding that women who suffer from FAS and FAE can be helped. Betty Cooper, the Director of the American Indian Family Healing Center, has admitted women with FAS and FAE into her treatment program and says "these women are begging for blueprints on how to be good parents."

From Dorris' book, however, you would not know that the birth mothers even existed. He did not interview the mother of an FAS child, or explore their lives. Instead, Dorris has supported the idea that women suffering from FAS should be put in jail for the duration of their pregnancy because he believes that these women cannot be helped. He says that a woman who herself suffers from FAS will be unable to "relate to a warning that '[n]ine months from now something bad is going to happen for the rest of your child's life if you drink today.'"<sup>1</sup>

He is not alone in his frustration. Although FAS and FAE are preventable diseases, its incidence has been called "an epidemic" on some reservations. According to the Director of the Clinical and Preventive Services of the IHS, out of every 10,000 Native American children, 29 are born with FAS and FAE, but for particular tribes -- such as the Apache and the Sioux -- the problem is far more serious.<sup>2</sup> One Native American woman, Jeaneen Grey Eagle, has said in The Broken Cord: "what we're talking about here is the

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<sup>1</sup> M. Dorris, The Broken Cord, at 179.

<sup>2</sup> Statement of Craig Vanderwagen, Director, Clinical and Preventive Services, Indian Health Service, Hearing Before the Senate Subcommittee on Social Security and Family Policy of the Committee on Finance, 101st Congress, Second Session (December 10, 1990) at 13.

survival of the Indian people."

While there is no basis for singling out Native American women's alcohol use as aberrational because there is no evidence that Native American women, as a population, consume more alcohol than women in the population as a whole, there have been some drastic measures taken against women who drink or use drugs during pregnancy, as has also occurred in the larger population. For example, the Navajo Nation tried to get heavy maternal drinking classified as prenatal child abuse under their Child Abuse Act. And in 1990 police arrested a Sioux Falls woman, who allegedly delivered a child with a positive toxicology for cocaine, and charged her with contributing to the dependency of a minor. She pled guilty to a lesser offense.

Yet, solutions for Native American women with alcohol and drug dependency problems have largely been ignored by the federal government. FAS prevention policy, originating around 1979, has been driven by the simplistic idea that women are primarily responsible for FAS and FAE and has focused primarily on the health of the fetuses, not of the women themselves. Long-standing policy has ignored the dearth of gender-sensitive treatment programs for women, the devastating health consequences of alcohol use on all Native Americans, and the complex conditions that give rise to alcohol dependency, including poverty, violence, and alcoholism within the family. Alcohol-dependent Native American women have become the quintessential "throwaway" population. Health care reform must address these problems.

### Getting money where it counts

The problems are many. Treatment providers complain that the system is often too slow to diagnose clients with FAS or FAE. "They end up," according to Cooper, "in our program with, on average, a third grade education." At least 30 percent of her patients, she believes, have FAS or FAE. Yet much of the federal money spent on "FAS prevention" -- an estimated \$10 million a year for each of the years 1992-1994<sup>3</sup> -- never reaches them.

For example, Jeaneen Grey Eagle testified in 1990, before the Senate Committee on Finance, that the government gave only \$20,000 to the Aberdeen area in 1990 -- an area that has one of the highest incidences of FAS and FAE -- for prevention, education and special needs.<sup>4</sup> In another example, Native Americans living in urban areas (approximately 49 percent in 1980)<sup>5</sup> are eligible, under IHS regulations, only for outpatient care and referral services.

Further, even when money is available, it is not always easy to get. Reagan's replacement of the federal categorical grant with the block grant process cut tribes out of the grant-making process

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<sup>3</sup> The Indian Omnibus Anti-Drug Abuse Act Amendments of 1990, Rept. 101-510, 101st Congress, 2d Session, Report of Mr. Inouye, from the Select Committee on Indian Affairs (Oct. 8, 1990) at 12.

<sup>4</sup> Hearing Before the Senate Subcommittee on Social Security and Family Policy of the Committee on Finance, 101st Congress, Second Session (December 10, 1990) at 23.

<sup>5</sup> Indian Health Care: An Overview of the Federal Government's Role, A Staff Report for the use of the Subcommittee on Health and the Environment of the Committee on Energy and Commerce, U.S. House of Representatives (April 1984) at 28.

making states the only eligible recipient of federal funds. Tribes located in rural areas suffer especially because states agencies tend to award money to tribes located in urban areas -- where the cost of treatment is much lower.

Funding methods also complicate the delivery of services. For example, the Guiding Star Lodge is funded partly by the Arizona Department of Health, which requires the program to serve Native American women living in Maricopa County. IHS, who provides the remaining money, requires the program to serve three state areas for Native Americans living only on reservations.

Also, according to Cooper, "people in legislatures and in policy-making positions still do not want to hear about it." Although Congress has convened numerous hearings, it was unable to pass an FAS prevention bill last year.

### Choosing a vision

It is impossible to examine FAS prevention policy, as formulated by the government, and not wonder why the government has not adopted a more comprehensive approach. After all, Congress has listened to hundreds of experts during dozens of hearings about this problem. Yet, like social attitudes driving policy towards women's health generally, federal programs attend to women most when they are pregnant. FAS prevention has meant, largely, that the federal government gives money to tribes to distribute education materials and to identify those suffering from FAS, and

gives money to the Center for Disease Control and various other agencies for surveillance studies.

Part of the blame must rest on the liquor lobby who is hungry, powerful, and heavy-handed. It has been discovered that some companies have planted people in meetings organized by treatment providers and health care workers, who then run back to their home offices to squeal about preventive measures in the works. The industry then counter-attacks with campaigns such as one put out recently by Coors -- a "pow-wow calendar" that pictures a seven-year old Native American girl dancing in beautiful regalia carrying a Coors sign on the placard bearing her competition number. Budweiser has made replicas of little Budweiser beers into chocolate and distributed it to all the reservations, thus ensuring that children will carry a Bud in hand before they can walk.

The License Beverage Industry Council (LDIC), formed in 1979 when the first serious effort to put warning labels on alcoholic beverages began, is more ingenious. The LDIC, funded by the liquor companies, recently gave \$40,000 to the Southern Governor's Conference on Infant Mortality for the publication of a treatment directory for programs in the South. They just sent the American Medical Association \$300,000 to produce a documentary about alcoholism. Rumor has it that they will provide more money for a documentary on drinking during pregnancy. Says Christine Lubinski, until recently the Director of Policy for the National Council on Alcoholism and Drug Dependence: "They'll use the name and goodwill inherent in those organizations to buy political cover on the Hill

for the next decade."

The bottom line is that FAS prevention policy is impoverished. It has ignored the impact of alcohol on the user herself. Women who give birth to children suffering from FAS and FAE are chronic alcoholics, often losing their lives to alcohol. The biological mother of Michael Dorris' son Adam, for example, died two years after he was born, after overdosing on antifreeze. As the authors of a report delivered to Congress in 1986 observed: "[a]mong Indian adolescents and young adults, the alcoholism death rate for females is 25-30 times the national average."<sup>6</sup> Moreover, "that the mortality rate is already more than ten times the national average among 15-24 year olds suggests that drinking begins early for Native American women."<sup>7</sup> Given this information, which has not been a secret, it is a crime that IHS did not fund a treatment program designed solely for women until one year ago.

Further, Native American women's broader health concerns have been left out of the policy-making process. The mortality rate for Native American women is higher than for U.S. women of all races, except in the 65 year and older range.<sup>8</sup> Native American women suffer higher rates of death from tuberculosis, diabetes, nutritional deficiencies, cirrhosis, gallbladder disease, non-

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<sup>6</sup> Judith Kitzes, Lawrence Berger, "The Health of Native American Women," Hearing Before the Select Committee on Children, Youth and Families, House of Representatives, 99th Congress, Second Session (January 10, 1986) (Y4.C43/2:N21/p6.3) at 224 (hereinafter Kitzes).

<sup>7</sup> Id. at 223.

<sup>8</sup> Kitzes at 216-218.



intentional injuries, respiratory and kidney diseases, and breast cancer.<sup>9</sup> Most alcohol dependent women have extensive clinical records for alcohol-related problems such as accidents, trauma, and alcohol withdrawal.<sup>10</sup> The majority of cirrhosis-related deaths are alcohol-related and account for one out of five deaths of Native American women ages 35-44.<sup>11</sup> Yet there are few treatment programs, or tribes, that have the medical staff to respond to these problems. Not surprisingly, rural areas are hit the hardest.

This vision also ignores the children who are not obtaining a variety of services they should be getting, including immunizations, routine eye and dental exams, rehabilitation medicine or prosthetic services. Nora Garcia, President of the Inter-Tribal Council of Arizona, and Chairperson of the Fort Mojave Tribe Council observes: "Behavioral and health problems of a child's caregivers, from molestation to poor parenting skills, domestic violence to lack of transport affect the level of care and attention given to children...."<sup>12</sup> Solutions must be devised to respond to all of these health problems.

Finally, this vision ignores families. This can be seen in at least two ways. First, it means that the government has not funded programs to help those whose behavior leads women to drink. Tribal

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<sup>9</sup> Id.

<sup>10</sup> Id.

<sup>11</sup> Id.

<sup>12</sup> Hearing Before the Select Committee on Indian Affairs, United States Senate, 102nd Congress, 2d Session on S. 2481, S. Hrg. 102-855, May 29, 1992 at 101.

participants at an IHS-sponsored conference entitled "Women and Wellness," held in 1991, identified alcohol abuse and domestic violence as the two biggest problems on reservations. As one Native American woman recently told me: "Just help our men and we can help ourselves."

Second, ignoring families has kept this a "woman's problem." Yet, alcohol and drug use has been linked to four of the five leading causes of death among Native Americans -- cirrhosis of the liver, accidents, suicides and homicides.<sup>13</sup> Children of alcoholics account for 80 percent of all adolescent suicides.<sup>14</sup> The death rate for Native Americans due to alcoholism, since 1982, is five and a half times that of the population as a whole.<sup>15</sup> These problems deserve the same kind of national attention that FAS has been receiving.

Yet, as of 1985, IHS had allocated only one half of one percent of its budget to alcohol and drug abuse programs.<sup>16</sup> As

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<sup>13</sup> Statement of Susan Shown Harjo, Executive Director, National Congress of American Indians, "Indian Juvenile Alcoholism and Eligibility for BIA Schools, " Hearing Before the Select Committee on Indian Affairs, United States Senate, 99th Congress, 1st Session (September 18, 1985).

<sup>14</sup> Statement of Hon. Daniel Inouye, Hearing Before the Select Committee on Indian Affairs, 102nd Congress, 2d Session on S. 2481, S. Hrg. 102-764 (April 1, 1992) at 123.

<sup>15</sup> W. Boyum, "Health Care: An Overview of the Indian Health Service," 14 Am. Indian L. Rev. 241, 248 (1989) (hereinafter Boyum).

<sup>16</sup> Statement of Susan Shown Harjo, Executive Director, National Congress of American Indians, "Indian Juvenile Alcoholism and Eligibility for BIA Schools, " Hearing Before the Select Committee on Indian Affairs, United States Senate, 99th Congress, 1st Session, September 18, 1985.

observed by Brenda Demery, a public health nurse on the Sioux reservation in Rosebud, South Dakota: "People are aware it's a problem, people say it's a problem, but when it comes down to putting money in a program or in making a real effort to do something about it, it's pretty much an individual effort." <sup>17</sup> Representative William Lehman, during hearings before the Select Committee on Children, Youth and Families in the House of Representatives in 1986 stated ironically: "If the Indians would substitute cocaine for alcohol, you could get lots of federal money." <sup>18</sup>

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The impact of this vision has made many FAS prevention efforts largely unworkable. Even if you funnel money into treatment programs, they must be "gender-sensitive" -- that is, they must be able to respond to women's needs, or else they will not be very useful. For example, according to Cooper, women in co-ed treatment routinely get lost in the process in ways associated with the substance abuse itself. She told me that she was forced to make her program "women only" after observing that as long as men were present the women would do their laundry, hem their pants, braid their hair, and refuse to speak in group therapy.

Moreover, almost no one will fund child care programs, a service that most treatment providers agree is absolutely essential. There are only about three programs that provide some

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<sup>17</sup> Dorris at 194.

<sup>18</sup> 99th Congress, 2d Session (1/10/86) at 55.

kind of child care: The American Indian Family Healing Center has ten beds for women and eight for their children; each woman may bring two children under five years of age. The Guiding Star Lodge has fifteen beds for women and fifteen for children. The Native American Rehabilitation Association can accommodate thirty children. Each of these programs always have a waiting list.

Lack of treatment programs, and the shame and stigma that is still associated with "coming out" contributes to the problem of finding answers. Admitting to a drinking problem often results in ostracism and punishment, which leads, according to Dr. Phillip May, an expert on alcoholism among Native Americans, to the migration of Native American women to border towns where their only friends are other alcoholics -- "a setting where less stigma is attached to the production of multiple FAS children" and to the prolongation of alcohol use.<sup>19</sup>

The vision also creates paralysis: the system has been plagued by bureaucratic infighting, lack of coordination between IHS and Bureau of Indian Affairs (BIA) and state agencies, lack of adequately trained staff, inadequate counselor-level professionals available for mental health treatment programs on reservations, schools that fail to instill confidence and high self-esteem, lack of coordination with tribal leadership, and lack of outpatient and aftercare programs.

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<sup>19</sup> Philip May, "A Pilot Project on FAS Among American Indians," from Alcohol Health and Research World, vol. 7, No. 2 (Winter 1982/83). in Hearing Before the Select Committee on Children, Youth and Families, House of Representatives, 99th Congress, 2d Session. January 10, 1992, at 201.

### Toward a new direction

There are hints that the tide may be turning. Dr. Eva Smith, the Acting Chief of the Alcohol Division at IHS, has seen to it that IHS spends its money on women's treatment. This year the IHS and the BIA met for the first time -- in history -- to talk about how they can better deliver services. Treatment providers are working to coordinate social service provision.

In addition, Senators Daschle and Bradley have just introduced a bill, at the prompting of the Coalition on Alcohol and Drug Dependent Women and their Children, that would give states the option of paying for residential treatment for pregnant women who are eligible for Medicaid. It would also extend the Medicaid option to the end of the twelfth month after pregnancy. Right now the Medicaid program is limited to the first two months, which makes long-term treatment impossible for poor women. In addition, the bill allocates an additional 240 beds for pregnant Native American and Alaskan women living in IHS areas. There are also now "primary prevention" workers who are going into the field and training people to identify high-risk youth in the schools, clinics and WIC offices, educating children, and providing support and referral services.

But problems remain. Primary prevention workers are scattered around the country. We are a long way from getting people in every needed area. The Daschle-Bradley Medicaid bill would fund only 1080 beds in 1994 and only 6,000 beds by 1998. The most recent FAS prevention bill, sponsored by Senators Daschle and Bingaman,

channels money into data collection, surveillance activity and basic research -- not gender-sensitive treatment, although the bill, according to one of Senator Daschle's staffmembers, would allow HHS to give money "for prevention programs that are developed by local communities." And in these difficult times it is hard to believe that money for expensive treatment programs will be forthcoming. After all, President Clinton gave in pretty quickly to pressure from those who did not support his seemingly uncontroversial proposal for children to have universal access to vaccinations.

### Conclusion

As long ago as 1970, IHS identified prevention and "comprehensive treatment of alcoholism" as deserving the "highest possible priority at all levels of administration." Over twenty years have passed and this just has not happened. How long will neglect and indifference be the driving force behind FAS prevention policy? There is a chance now, with the coming of the Clinton Administration, that this will change. But it will take commitment, courage, and leadership.

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Kary L. Moss, Executive Director of the NLG/Sugar Law Center for Economic and Social Justice. She is currently editing a book about women's health care issues for Duke University Press. She would like to thank Betty Cooper, Dr. Wendy Chavkin, Susan Galbraith, and Dr. Eva Smith for their assistance in the preparation of this article. This paper was printed in the manual for the Seventh Annual International Conference on Drug Policy Reform (November 17th-20th, 1993) and will also be presented at a conference sponsored by the American Society of Criminology in November 1994.

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